STUDY ON STIGMA AND DISCRIMINATION TOWARDS TUBERCOLUSIS (TB) PATIENTS IN KANGRA DISTRICT OF HIMACHAL PRADESH

SYNOPSIS

Submitted in partial fulfilment of the requirements for the award of the degree of

DOCTOR OF PHILOSOPHY
in
SOCIOLOGY

Submitted by

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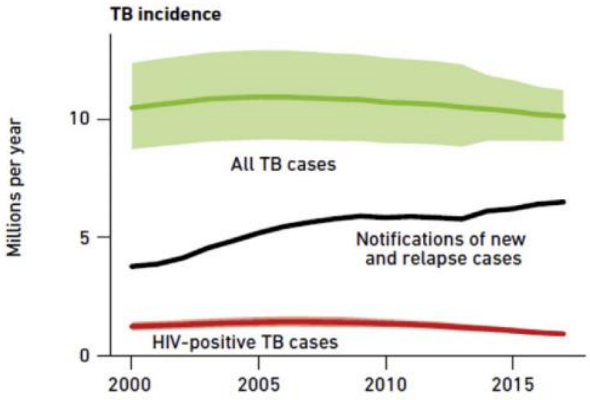
Introduction

Mycobacterium tuberculosis, an ancient human illness that primarily affects the lungs, is the cause of tuberculosis (TB), with pulmonary disease being the most typical manifestation(Terracciano et al. 60)but TB presents itself in a variety of ways since it affects multiple systems. The respiratory system, gastrointestinal (GI) system, lymphoreticular system, skin, central nervous system, musculoskeletal system, reproductive system, and liver are the organ systems most impacted(Mbuh et al. 2).

TB or illnesses resembling TB have been described fromdifferent civilizations since ancient times. The earliest suchdescription can be found in Vedas, where TB was referred to asYakshma meaning wasting disease. Greek, Chinese, andArabic literature also describes TB like disease. Mycobacterium exists on earth since last 150 million years. Typicaltubercular vertebral lesions were seen in mummies from theEgyptian pre-dynastic era and Peruvian pre-Colombian era.The first weak evidence of TB in humans is from a bone lesionfound in a 500-thousand-year-old skull in Turkey.

M. tuberculosis bacilli have infected nearly 1/3rd of the world'spopulation with 10% lifetime risk of developing TB disease(Bhardwaj et al. 29). Globally 10.4 million cases of TB reported in 2017, accounting to 133 cases/1,00,000 population, of which 90% of casesere adults (aged 15 years), 64% were male, 9% were peopleliving with HIV (72% of them in Africa) [Fig. 1]. An estimated558 000 new cases (range- 483 000-639 000) of Rifampicinresistant TB (RR-TB), of which almost half were in threecountries: India (24%), China (13%) and the Russian Federation(10%)(Global Tuberculosis Report). Among 0.8 million new EPTB cases reported worldwide in 2013, maximum cases were from India accounting for 0.35million cases(World Health Organization). In India, according to Revised NationalTuberculosis Control Program (RNTCP) data, the prevalence of EPTB is 50% in HIV infected patients and 15e20% innon-HIV patients. The distribution of EPTB was in lymph node47%, pleural cavity 30%, abdomen 10%, bones and joints 8%,CNS 2% and others 3%(Shrivastava et al. 223). Between 2000 and 2017, TB mortalityrate reduction is 42%. TB incidence has fallen by an average of2% per year and case fatality rate of 16% in 2017, down from23% in 2000(*Global Tuberculosis Report* 12). In 30 high burden countries, India has managedto reduce the prevalence rate by 50% as set by Stop TB Partnership Program. Drug resistant TB has been reported fromearly days of introduction of

ART, but multidrug-resistanttuberculosis (MDR-TB) and more recently extensively drugresistant tuberculosis (XDR-TB) posing a threat to TB controlprogram globally.



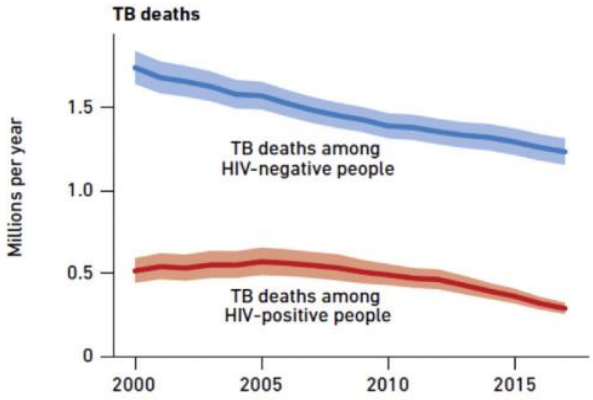


Figure 1(a): **Figure 1(b):**

Shows an estimated number of incident TB cases and TB deaths (in millions) from 2000 to 2017 according to Global Tuberculosis Report

Despite improvements in TB control and a drop in new cases and mortality, TB continues to carry a heavy burden of morbidity and mortality throughout the world. Six nations—India, Indonesia, China, Nigeria, Pakistan, and South Africa—accounted for 60% of TB deaths in 2015, bearing the majority of the global burden of new infections and TB deaths. (Pan et al. 1281–82).

Globally, tuberculosis is prevalent. However, a disproportionate amount of the burden of tuberculosis is borne by underdeveloped nations. Several nations in Asia, Africa, Eastern Europe, Latin and Central America, as well as the six nations mentioned above, continue to have an unacceptable high burden of tuberculosis.

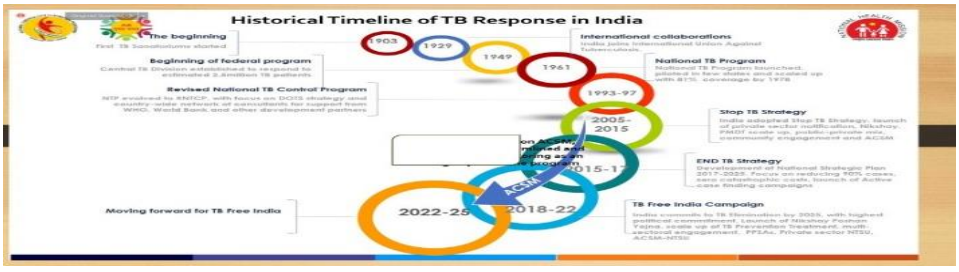


Figure 2: Historical timeline of TB response in India

Compared to the national average of 1%, Himachal Pradesh has a 1.9 percent annual risk of tuberculosis infection. In Kangra, an updated national tuberculosis control programme (RNTCP)

was launched in October 1998. They used the 5-year (2001-2005) Kangra RNTCP secondary data to assess the program's effectiveness. Extrapulmonary instances ranged from 56 to 73 percent, whereas 15-20 percent is considered normal. 42 to 48 percent is the range for category 1's greatest percentage. The detection rates for new smear positive cases (78–90%) and cure rates (88–91%) were the highest compared to data for the state and the nation. Kangra Tuberculosis Units (TU) had the highest failure rate at 6.5 percent, and TU Palampur had the highest default rate at 7.2 percent. Following the implementation of RNTCP in 1999, tuberculosis cases decreased from 6,462/100,000 in 1999 to 2,195/100,000 in 2005. Males were more affected than females in both age (15-55) and sex terms (59-64 percent)(Sagili et al. 5). Person who is affected has poor mental and social healthpreventing him from seeking therapy or from adhering to the prescribed course of action, which could potentially have an impact on the course's success(Aryal et al. 48)

A serious public health issue around the world, TB is a chronic infectious illness that negatively impacts the health of millions of individuals every year. Patients with TB have a pervasive stigma that is similar to that experienced by persons with leprosy, HIV/AIDS, and the acquired immune deficiency syndrome (AIDS)(Abebe et al. 2). This has negative effects on TB patients since it can be felt in a variety of social settings, including the family, workplace, and community(Shivapujimath et al. 2). For TB prevention and control, stigma connected to the disease has grown to be a severe obstacle(Cremers et al. 2). Although TB stigma is a significant social issue, there is also increased awareness of the need to combat it(Abioye et al. 101).

Literature Review

Jaggarajamma K et alin their research paper “Psycho-Social Dysfunction: Perceived and Enacted Stigma among Tuberculosis Patients registered under Revised National Tuberculosis Control Programme: An Observational study in India” published in 2008 found that the study TB patients 276 registered for treatment during January-March 2004 in government health facilities of two Tuberculosis Units of south India.Of the 276 patients, 190 (69%) were males. There was no significant difference between the genders in relation to social stigma. Perceived stigma was higher than enacted stigma in both genders and significantly higher among males (Low self-esteem $p < 0.05$), change of behavior of community ($p < 0.05$), ashamed to cough in front of others ($p < 0.05$)(Jaggarajamma et al. 179–182).

VK Dhingra and Shadab Khanin their research paper "A Sociological Study on Stigma among TB Patients In Delhi: A Prospective Study in India" published in 2010 found that newly diagnosed and registered cases under Revised National TB Control Program for treatment during the period of March 2009 to May 2009 were included in the study.There was an immense stigma observed at society level with 60% of the patients hiding their disease ($p<0.05$) from friends and neighbors. Stigma was observed more among middle and upper middle class when compared to lower middle class and lower class ($p<0.05$). Gender-wise further it was observed that stigma was more among females ($p<0.05$) than in males(Dhingra and Khan 12–13).

Tanu Anand et alin their research paper titled "Perception of Stigma Towards TB among Patients on DOTS & Patients attending General OPD in Delhi: A Cross-Sectional Study in India" published in 2014 has concluded that the total of 100 patients on DOTS and 200 patients from general OPD were interviewed. There were 21 patients who reported to have delayed treatment seeking due to stigma. Nearly one third patients (n=34; 34%) noted negative changes in the behaviour of their family members towards them while 40% were isolated on being diagnosed with the disease. Out of the 36 employed TB patients, 65.5% (n=23) experienced negative change in the behaviour of their colleagues. In general, OPD patients, significantly higher proportion of female patients said that they would not disclose the disease status of a family member suffering from TB to their neighbours ($p<0.001$)(Anand et al. 35–36).

Sagili et alin their research paper "Is Knowledge Regarding Tuberculosis associated with Stigmatising and Discriminating Attitudes of General Population towards Tuberculosis Patients" published in 2016 has found that from a Community Based Survey in 30 Districts of India. Of the 4562 interviewed, 3823 were eligible for the current analysis. Of these, 73% (95% CI 71.4-74.2) had stigmatising and 98% (95% CI 97.4-98.3) had discriminating attitude towards TB patients. Only 17% (95% CI 15.6-18.0) of the respondents had appropriate knowledge regarding TB with even lower levels observed amongst females, rural areas and respondents from low-income groups. Surprisingly stigmatising (adjusted OR 1.31 (0.78-2.18) and discriminating (adjusted OR 0.79 (0.43-1.44) attitudes were independent of knowledge regarding TB(Sagili et al. 1-5).

Mukerji et al. in their research paper "Explored Manifestations of TB-Related Stigma Experienced by Women in Kolkata, India: A Cross-Sectional Study in India" published in 2018

found that indicated TB stigma mainly manifested through social isolation and avoidance due to fear of contagion, gossip and verbal abuse, failed marriage prospects, and neglect from family. Consequences of stigma described by the women included non-disclosure, feelings of guilt, and mental health issues including suicidal ideation. Positive coping strategies used by women to cope with the experiences of stigma included positive reframing, prayer, talking to other patients, focusing on schoolwork, and relaxation activities. Negative coping activities included self-imposed social isolation and anger. In some cases, non-disclosure due to stigma had an impact on TB transmission and control behaviors(Mukerji and Turan 725–26).

Sunil et alin their research paper "Study of Social Stigma among Tuberculosis Patients from Northern India: An Observational Study in India'' published in 2019 has found that the in total approximately 65.3% of subjects experienced stigma. Out of these, around 42% were afraid of disclosing illness to his or her friends. Almost 31% did not disclose their illness to friends. In 20% of the cases, their friends avoided them after knowing about their illness. About 64% were afraid of disclosing illness at place of work. Almost 34% of study subjects did not disclose their illness at workplace. Problems related to marriage prospects were expressed by 48.6% of unmarried female patients(Sunil et al. 978–80).

Kamble et alin their research paper "Social Stigma among Tuberculosis Patients attending DOTS Centers in Delhi: A Cross-Sectional Study in India" published in 2020 found that the mean age of patients was 31.5 years (SD ± 11.5) with age ranging from 18 to 77 years. Males were higher (57.4%) compared to females (42.6%). 123 (45.5%) perceived stigmata with family/friends and 92/158 (58.2%) perceived stigma at workplace. Young patients (<30 years), males faced more stigma at workplace and lower socioeconomic class faced higher stigma with family and friends ($P < 0.05$)(Kamble et al. 4223–25).

Chen et alin their research paper "Tuberculosis-Related Stigma and its Determinants in Dalian, Northeast China: A Cross-Sectional Study" published in 2021 has found that the total of 601 eligible participants were recruited. The mean score for TB-related stigma was 9.07, and the median score was 10. The average scores for anxiety, social support and doctor-patient communication were 4.03, 25.41 and 17.17, respectively. Multiple linear regression analysis revealed that patients who were female ($\beta = 1.19$, 95% CI: 0.38–2.01, $P < 0.05$), had self-assessed moderate or severe disease ($\beta = 1.08$, 95% CI: 0.12–2.03 and $\beta = 1.36$, 95% CI: 0.03–

2.70, respectively, $P < 0.05$), and had anxiety ($\beta = 0.38$, 95% CI: 0.30–0.46, $P < 0.001$) were more likely to have a greater level of TB-related stigma than their counterparts. (Chen et al. 2–6).

Research Gap Identification

Stigma and consequent discrimination can make a drastic impact upon a person's overall health both mental as well physical health. This is true in cases of many major/serious diseases such as AIDS, Cancer etc. But in case of tuberculosis, people generally think that it is just a common disease, thus, don't take into consideration the stigma and related discrimination which that person faces on daily basis because of TB.

There have been a numerous researches encompassing the detailed study of dishonor or shame faced by people suffering with diseases or even with tuberculosis worldwide and even in many states of India. All these research endeavors have displayed how these people feel and how they are discriminated by society or sometimes even by their own family members because of the fear of getting infected. Such studies have concluded many measures adopting which can bring change in the outlook of people at large.

The state of Himachal Pradesh is also affected with the same perception towards the patients suffering with tuberculosis. But the research endeavors to measure the attitudes of people of Himachal Pradesh are very few. In such direction, the present research proposal aims to measure the level of Stigma and related discrimination of people towards the tuberculosis patients especially in the district of Kangra. This proposed research work will bring into limelight the reasons and preventive measurements as well as how to bring a change in the attitude of people towards the patients suffering with tuberculosis.

OBJECTIVES

1. To study the stigma and discrimination towards TB patients.
2. To study the attitude of the family members and neighbors towards TB in Kangra district of Himachal Pradesh
3. To suggest comprehensive strategies for creating awareness and knowledge about TB among the community to eliminate stigma and discrimination and to create empathy towards TB patients.

Hypothesis

For the present study the investigator had formulated null hypothesis that:

1. There is no significant difference between sigma and discrimination towards TB patients.
2. There is no significant difference between the attitude of family members neighbors towards TB in Kangra district of Himachal Pradesh.
3. There is no significant difference between the comprehensive strategies for creating awareness and knowledge about TB among the community to eliminate stigma and discrimination and to create empathy towards TB patients.

Proposed Methodology

For any kind of research study methodology is an important aspect. By methods we mean systematic approach toward a particular phenomenon. To carry out the research work proper methods and proper procedure should be followed. The present chapter deals with the methods and procedure adopted in conducting the present study. It includes the descriptions of the research method, sampling, population, sample variable, instrumentation, data collection and statistical technique.

a) Methods of Research

Fornthe current research proposal, the "survey" method of research under the descriptive type of research will follow. Further, analytical method will be utilized to collect and provide the required information with regard to stigma and discrimination towards TB patients implemented in district Kangra of Himachal Pradesh.

b) Inclusion Criteria

i. Patients who were diagnosed with tuberculosis as per Revised National TB Control Program (RNTCP) and availing treatment from the DOTS centers.
ii. Patients of age more than 18 years.

c) Exclusion Criteria

The following patients were excluded:

i. Debilitated patients
ii. Patients with other comorbid illnesses including HIV infection, diabetes, and other chronic diseases.

d) Data Collection

For collection of data, a personal approach following one-to-one interaction will be followed. The persons (TB Patients) for collecting samples will selected randomly based on the availability of spare time on part of person selected. After the random selection, the investigator will provide TB patients the Questionnaire to fill so to collect the required data for the proposed research**.**

e) Statistical Technique used.

For establish in the difference in the 't' test will be employed and for relationship person product moment correlation method technique will be used.

Thesis Outline

The study will be divided in five chapters which will be headed as:

Chapter 1: **Introduction**

The introduction provides for the research design consisting of the problem profile, review of literature, objectives of the research, research questions, research methodology and research aim, chapterization on the entire study.

Chapter 2: **Review of Literature**

Deals with the literature review, stigma and discrimination towards TB patients research study it definitely helps the researcher to imbibe his awareness and understanding of various techniques available for conducting such as investigation and gleaned and complied with great effort. The review is based on various sources like journal, Periodicals, Unpublished theses, internet etc. The review also helped to develop the understanding and concept that contributed to the overall rational interpretation of data.

Chapter 3: **ProposedMethodology**

Discuss the study's research methodology. This Chapter covers the Sampling process, total sample size, data sources, method and tools for gathering data, as well as the processing and preliminary analysis of the data.

Chapter 4: **Result and discussion**

The most important part of research is the presentation, analysis and interpretation of data in a systematic and objective way. Analysis of data means studying the tabulated and classified raw

material to determine meaningful inherent factors. Analysis and interpretation is the heart of research. Tabulated data have no important without its interpretation.

Chapter 5: **Summary and Conclusion**

Discuss the creation of stigma and discrimination towards TB patients, how they operate and the entire study concluded with further suggestions.

Chapter 6: **References**

The 9th edition of the MLA Handbook will be adhered strictly for proper in-text citations and references.

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CERTIFICATE

(SYNOPSIS APPROVAL CERTIFICATE)

This is to certify that the Revised Synopsis for Ph.D. Thesis titled, **"Study on Stigma and Discrimination Towards TB Patients in Kangra District of Himachal Pradesh"**, submitted by **Ms Urmila Devi** to the Career Point University, Hamirpur (H.P.), India in partial fulfillment of the requirements of the degree of **DOCTOR OF PHILOSOPHY** in the Division of Language, Journalism and Social Sciences, School of Management and Liberal Arts has been approved by the Research Advisory Committee (RAC) after an oral examination of the student on dated 17th July, 2023.

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